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FOIA MARKER

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Record Group/Collection:	Donated Historical Materials
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Series:	Related Materials
Subseries:	Speeches

OA/ID Number:	52090
Folder ID Number:	52090-013

Folder Title:
IL [Independent Living]/ADA/Aging Speech [n.d.]

Stack:

Row:

Section:

Shelf:

Position:

— will health care
next to go

— in 10 to (2) common
issues " 2 also 3

HCFP
healthcare
home care
housing

} risk & quality
solutions

Healthcare — ^{healthcare} closely w/ influence
as @ risk
long term care ignored

Home care — Qs w/ influence
as @ risk
(re separated issue)

Housing — needs rethinking

Below, we need a
unified coalition
strategy

Building a take-ownership

supported by
experience
knowledge
consensus
support
financial and
moral

Rehab Act

Older Consumer Act

aging w Disability (But not all)

1. top of interest

Dis age

crossing
pop

2. older people who become
dis - many as a
result of natural
aging process

3. younger dis people
w a history of dis who
are getting old

4. older people who have
trauma and who
cannot attribute
cause to aging

①

To effect influence
crossing policy, policy ^{larger} groups
must coalesce
not just common subject

②

To effect coalesce,
common issues must be present
and realized

Neither 1 nor 2 has
happened

thus 3 big opportunities missed
tax reform
housing reform
Medicaid/Medicare reform

Groups are alike
in some ways
(e.g. diagnosis)
functional impairment
different in others
(adaptability
& approach
attitude)
Prognosis will differ

my pleasure ↑

Based on that premise
my conclusions
relating to Public
Policy

Independent Living ~~Centers~~ or Supported Living Supported Living

researchable issues

Is there a correlation between Post Polio Syndrome and ageing experiences of other disability groups

How do ageing and other disability groups vary and how are they alike

What are the requisite conditions for ageing disabled people to respond to rehabilitation (rehabilitation includes interventions other than restorative therapy -- psychological and I & L counseling, use of ~~the~~ technology, environmental adaptations

Thank

Independence Ct.
ACOTA & NVO/2A
Dorothy Rowe
Bruce
Bowie
Pharo

Honor & opportunity
to share views
to part of the future
part of outstanding Program
excellent presenters

Consumer Advisory: Lessons
to Learn from the Dr. Movement

Diff. subj. & slightly awkward
Dis-must learn from giving
many authorities - to me
in movement

On the other hand
Dis-movement good on
'L & Rights
proof of account
want to share

The Council is authorized by statute to contract for technical and administrative assistance, \$43,000 is budgeted for these services for FY 1989. The Council believes that their GSA contract provides the most efficient and cost-effective alternative for assistance with personnel matters, contracting, regulation development and overall conformity with Federal rules and practices, as required of independent agencies such as the Council.

In addition to using expert contractors to develop specific data and background information, the Council uses, on a contractual basis, interpreters for hearing-impaired and deaf members and public participants, readers for visually-impaired and blind members and public participants, and personal assistants for members and public participants who are severely physically disabled. The temporary employment, by contract, of such providers is directly related to the nature of work performed by the Council and to the explicitly stated policy of affirmative action to which the Council subscribes. The Council also must employ, on a contractual basis, recording professionals and public transcription specialists to record Council meetings and produce minutes of these meetings for the public record. Additionally, meeting space and public address systems for meetings must be secured on a contractual basis. For these purposes \$40,000 is budgeted for FY 1989.

The Council will conduct a series of briefings for members of Congress and their staffs during FY 1989 on issues of particular concern to the Administration and the disabled community. The Council also will continue to participate in such activities as those associated with the annual meeting of the President's Committee on Employment of the Handicapped in order to fulfill its statutory mandate.

In terms of representation and reception, although the Council's authorizing statute allows for up to 10 percent of the Council's funds to be spent for official representation and reception, no funds are being requested for this purpose. This is done in an effort to assist the Administration in conserving funds and reducing administrative expenses.

Ten thousand dollars has been budgeted for miscellaneous contractual services and expenses in FY 1989. The amount budgeted under miscellaneous for FY 1989 will be used to pay for small, unexpected purchases not included in other budget line items. These purchases may include the purchase of such items as maintenance services for equipment and public service announcements.

SUPPLIES

The Council's budget includes \$15,000 for purchase of supplies during FY 1989. This amount includes ordinary office supplies such as paper, pens and pencils, etc. Funds also are budgeted for the purchase of computer software, library materials, and for subscriptions to relevant scientific, technical, and policy-oriented publications.

what is the rights

1/2

dis. movement

= people w common
concerns about
2 sets of issues

services - 12

attitudes - dis rights

most obvious members

are consumers

providers
family members

movement by positives

#1 revolutionize

service system

redesign →

change vectors in

1989 BUDGET POLICY

The National Council on the Handicapped's budget request for FY 1989 is in the amount of \$974,000.

PERSONNEL

For FY 1989 the Council requests a budget of \$330,000 for salary expenses associated with full-time permanent employees. This amount represents the projected actual cost of maintaining FY 1988 staffing levels. It also includes pay raises for 1988 and 1989, as well as the effects of FERS.

The Council staffing pattern assures one professional staff person in each of the following major areas of Council responsibility: Adult Services, Children's Services, Research, and Public Affairs. Each area is specific and requires an exclusive body of education and professional experience. Each of the four professional staff persons is responsible for staff assistance to a specific Council committee having policy responsibility for the same area as the professional staff member.

The position of Executive Director is authorized in the Council's statute and is responsible for evaluation of overall staff performance. The three administrative staff members include a staff assistant and two secretaries who perform typing, filing, record-keeping and other supportive functions.

Sixty-six thousand dollars is budgeted for other personnel compensation and benefits during 1988. This amount includes \$5,000 for employee awards and overtime pay, and \$61,000 for personnel benefits. No increase is requested for awards and overtime from the prior year. Personnel benefits are a direct function of the amount of budgeted salary and wages.

Council Members

One hundred and four thousand dollars is budgeted for compensation of Council members during FY 1988. Council members are paid at the GS-18 grade rate as authorized by statute. This budgeted amount reflects a desire by members to be actively involved with the activities and affairs of the Council.

At the present time, the Chairperson and members of the Council are involved in a number of interagency working groups and advisory committees requiring their participation at frequent meetings in Washington, D.C. These working groups and committees include; the Interagency Committee on Handicapped Research, the Interagency Committee on Developmental Disabilities, and the Social Security Administration working group on disability issues. Each of these interagency committees and working groups is authorized by Federal statute.

Reorient system

more → community

availability

cost

→ responsiveness

more → indep.

self control

★ →

dignity

self

responsibility

responsibility

more ← →

away from

institutions

forced dependency

~~indep prescription~~

~~prescriptive model~~

authoritarian professional

PLANNED ACCOMPLISHMENTS SUMMARY FOR FY 1989

During the 1989 Fiscal Year, the Council will continue its follow-up and monitoring activities pursuant to the Congressional mandate to assess progress made on each of the 45 legislative recommendations in its 1986 report, Toward Independence. The 1989 report may contain data on such subjects as health, housing, employment, insurance, transportation, recreation, and education.

The Council will continue to address its statutory responsibilities to establish general policies for the National Institute on Disability and Rehabilitation Research and the President's Committee on Employment of the Handicapped, as well as provide recommendations and advice to the Commissioner of the Rehabilitation Services Administration.

To assure coordination of programs and services affecting people with disabilities, the Council also will continue its participation in such initiatives as the Interagency Committee on Handicapped Research, the Federal Agency Council, the Federal Task Force on Disabled Persons, and other similar coordinating bodies.

Input from consumers is critical to the Council's process of policy development. As in the past, input will be solicited at four public forums on topics such as: parents of children with disabilities, institutional reform, the problems of homeless persons with disabilities, employment opportunities for persons with severe disabilities, and recreation opportunities. Specific technical information also will be solicited on an individual basis from the Council's advisors.

A major activity scheduled for FY 1989 is a conference to bring together families who have children with disabilities to encourage a continuing dialogue among them and to determine their needs. Another important area which the Council will be pursuing is the feasibility of the development of a National Commission on Excellence in Special Education. Studies on education issues such as due process rights, least restrictive environment, and children with disabilities who are particularly difficult to integrate also will be explored.

Objective II

5

establish rights
change (improve)
attitudes

overcome division

~~seek integration~~

move → rights
assumed equality
integration

inclusion
raised expectations

Self advocacy

move ↔

charity
acceptance
denial

FRUSTRATION

for an outstanding professional whose expertise was in the area of Native Americans. This program continues to be mutually beneficial for the fellows and the Council.

Finally, in order for the disability community and others to know more about the activities of the Council, circulation of the Council's newsletter, "Focus" was expanded. The newsletter continues to be a vehicle for communication and helps the Council solicit input regarding its activities and policy development.

Change started

6

Progress → objectives

- 1 L centers

Transpo.

File NY

late att'd core

Housing Design

employment 169 (SSI)

AAA model
COBS

Some believe change & results
from change ↓

- rights ↓

50% / restoration cost

Lab progress

housing - Fl NY

att'd core - Calif, PA,

local progress

Transpo - Sewer

since - 73
results of test
advocacy
logs, att'd, 60%

ACED
NCL

sit-ins
ADAPT
Hollandet

Rehabilitation Research (NIDRR), the Council reviewed the operation of NIDRR in areas such as: the development of general policies; the priority planning process; and the Interagency Committee on Handicapped Research (ICHR).

A new duty which Congress assigned to the Council in the 1986 Rehabilitation Amendments was to establish general policies for the President's Committee on Employment of the Handicapped (PCEH). As a result of this charge, the Council convened meetings and provided input to PCEH.

In an effort to gather valid and reliable data regarding the life circumstances of persons with disabilities, the Council has been involved in three Harris polls. In Fiscal Year 1986 the Council initiated the first ever, nationwide Harris poll survey of Americans with disabilities. Subsequent to the Harris survey, the Council analyzed the survey's implications for the Federal Government in a document entitled, "Federal Policy Implications of the Harris Poll." The Council initiated a second Harris poll focusing on employers' perceptions of persons with disabilities which was conducted by the International Center for the Disabled. The Council has provided assistance with a third Harris poll dealing with the education of children with disabilities. The results of the education poll are scheduled to be released in May of this year.

As the primary Federal agency with responsibility for "reviewing and evaluating all policies, programs and activities concerning handicapped individuals...", the National Council on the Handicapped continuously seeks to receive input and feedback from consumers with disabilities. Conducting forums in different parts of the United States, on a variety of topics, is one way of seeking input. In FY 1988 the Council conducted forums on topics such as native Americans with disabilities, the draft equal opportunities proposal, and the problems of children in institutions. The Council also maintains a list of disabled consumer advisors whose expertise is highly valued and utilized on many issues.

Another way to be involved in issues of concern to disabled persons is to cosponsor conferences and meetings. During FY 1988 the Council cosponsored conferences on topics such as the status of college students with disabilities with the Association of Handicapped Student Services Personnel and the community integration of persons with mentally retardation with the President's Committee on Mental Retardation. The Council also cooperated with the President's Committee on Employment of the Handicapped in conducting meetings on equal opportunities and minorities with disabilities.

Participation in a wide array of interagency committees enables the Council to keep abreast of activities in the Federal Government, as well as keeping others informed of the Council's activities. Membership on the Interagency Committee on Handicapped Research, the Federal Agency Council, the Federal Task Force on Disability, the Interagency Committee for Computer Support of Handicapped Employees, and the Interagency Committee on Developmental Disabilities reflects this policy of cooperation.

Facilitating educational experiences through a fellows program for mid-level professionals has been another area in which the Council has been involved for four years. In Fiscal Year 1988 the Council again sponsored a fellows program

Needs Now

Services
expansion

funding

appropriation
depts - Pepper
Chaffee

~~Right~~

Fair Housing
Rights Coord.

ADA

LEADERSHIP
COALITION bldg,
OUTREACH

Enthusiasm
Passion

Identification code 95-3500-0-1-506		19 87 actual	19 88 estimate	19 89 estimate
<u>Program by activities:</u>				
10.00	Total obligations	853	872	974
<u>Financing:</u>				
25.00	Unobligated balance lapsing	7	20	-
40.00	Budget authority (appropriation)	860	892	974
<u>Relation of obligations to outlays:</u>				
71.00	Obligations incurred, net	853	872	974
72.40	Obligated balance, start of year	206	257	183
74.40	Obligated balance, end of year	-257	-183	-234
77.00	Adjustments in expired accounts	- 9	-	-
90.00	Outlays	793	946	923

FOUR ROLE

to introspect
 do self assessment
 reorient attitudes

examine attitudes
 values
 objectives
 behavior

change behaviors etc.
 if nec.

Don't accept
 status quo
 question the system

Identification code 95-3500-0-1-506	1987 actual	1988 estimate	1989 estimate
Total number of full-time permanent positions	8	8	8
Total compensable workyears: Full-time equivalent employment	9	10	10
Full-time equivalent of overtime and holiday hours	-	-	-
Average GS grade	11.75	11.75	11.75
Average GS salary	34,222	39,116	41,311
(Memo cost: 21.5)	-17- (Memo cost: 5)	(Memo cost: 5)	(Memo cost: 4.9)

9
Team Role
find ways to
teach
promote
bring
facilitate

indep.
in indiv clients
& in the system

learn to be
an advocate -

Advocate or parent/professional
recognize the possibilities
for clients
transfers
for children
encourage

participate in
decision-making
self advocacy
responsibility

MAJOR ACTIVITIES SUMMARY: FISCAL YEAR 1988

Major highlights of the Council's 1988 Fiscal Year activities include the completion of the congressionally mandated report, On the Threshold of Independence, the development of a comprehensive draft legislative proposal prohibiting discrimination against persons with disabilities, and progress on the prevention of disabilities initiative.

On the Threshold of Independence describes progress made toward implementing the 45 legislative recommendations presented in the Council's 1986 report to Congress and the President, Toward Independence. Based on an analysis of proposed legislation, new statutes, and administrative activities, approximately eighty percent of the Council's recommendations have been acted upon to some degree. The title, "On the Threshold of Independence" refers to the fact that for people with disabilities, some of the doors to opportunity have been opened, some are ajar, and some still remain firmly shut.

A major recommendation of Toward Independence was the development and enactment of a comprehensive law prohibiting discrimination against persons with disabilities. The Council, along with the guidance and support of hundreds of consumers with disabilities, parents of children with disabilities, advocates, and others, has developed such a draft bill. The Council continues to believe that equality of opportunity is a bedrock right in our society, and that discrimination against people because of their disabilities is an unacceptable denial of that right.

Another priority emanating from Toward Independence was the need for a Federal initiative to prevent primary and secondary disabilities. Such an initiative could substantially reduce the costs of disability and health care for Americans, reduce the Federal spending for disability in the near future, and decrease the incidence of disability for future generations. Because it is clear that our Nation has the knowledge, technology, and resources to mount an effective and successful national program for the prevention of primary and secondary disabilities, the Council has devoted concerted effort in this area, and considerable progress has been achieved in the past two years.

Congress recently allocated \$3.8 million to the Centers for Disease Control for a small community-based grants program on prevention. This program, still in the initial stages, will have four components: 1) state-based steering committees; 2) state-based prevention units; 3) community-based projects; and 4) CDC research activities. In addition to CDC efforts, the Council is also working closely with the Office of Disease Prevention and Health Promotion to develop a national plan on the prevention of disabilities comparable to others they have developed.

The Council actively participated in the regulatory process for pieces of legislation affecting the lives of persons with disabilities by providing expertise in areas such as the newly established early intervention program for infants and toddlers with disabilities under the Education for the Handicapped Act, as amended.

Pursuant to its ongoing statutory mandate to establish general policy for and review the operations of the National Institute on Disability and

org groups, coalesce, study issues 10
Sense the opportunity
join the movement
~~Reach for the P~~
Discover the Passion
!

People will live
— but how?
(more Disabled — longer)
Whose responsibility
is concern

TEN YEARS from now
will you be part of the
action
or will you be obsolete

search affecting persons with disabilities and the activities of RSA and NIDRR;

- ☐ **reviewing and approving standards for Projects with Industry programs;**
- ☐ **providing to the Congress, on a continuing basis advice, recommendations, and any additional information which the Council or the Congress considers appropriate; and**
- ☐ **issuing an annual report to the President and the Congress on the progress that has been made in implementing the recommendations contained in the Council's January 30, 1986, report, *Toward Independence*.**

While many government agencies deal with issues and programs affecting people with disabilities, the National Council is the only Federal agency charged with addressing, analyzing, and making recommendations on issues of public policy which affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual circumstance. The Council recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by assuring an informed and coordinated approach to addressing the concerns of persons with disabilities and eliminating barriers to their active participation in community and family life.

Change is coming
evidence now
more to come
and faster

It must

It will

We can be part of the
evolution/solution

or
we can watch it
go by!

Let us seize the
opportunity to be
leaders!

Thank You
Carol Brown

Thank You

Description of the National Council on the Handicapped

The National Council on the Handicapped is an independent Federal agency comprised of 15 members appointed by the President and confirmed by the Senate. The Council was initially established in 1978 as an advisory board within the Department of Education (Public Law 95-602). The Rehabilitation Act Amendments of 1984 (Public Law 98-221) transformed the Council into an independent agency.

The current statutory mandate of the Council assigns it the following duties:

- ☐ establishing general policies for and reviewing the operation of the National Institute on Disability and Rehabilitation Research (NIDRR);
- ☐ providing advice to the Commissioner of the Rehabilitation Services Administration (RSA) on policies and conduct;
- ☐ providing ongoing advice to the President, the Congress, the RSA Commissioner, the Assistant Secretary of the Office of Special Education and Rehabilitative Services (OSERS), and the Director of NIDRR on programs authorized in the Rehabilitation Act;
- ☐ reviewing and evaluating on a continuous basis the effectiveness of all policies, programs, and activities concerning handicapped individuals conducted or assisted by Federal departments or agencies, and all statutes pertaining to Federal programs, and assessing the extent to which they provide incentives to community-based services, promote full integration, and contribute to the independence and dignity of individuals with disabilities;
- ☐ making recommendations of ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting handicapped persons;
- ☐ reviewing and approving standards for Independent Living programs;
- ☐ submitting an annual report with appropriate recommendations to the Congress and the President regarding the status of re-

2
Common ground
dis people dif (types
et
but alike →

common need for
services

home care
nursing care
adapted transport
" housing
habilitative drives

Common victims
negative attitudes
of disenfranchisement
stigma
segregation
paternalism
dehumanization
discrimination
political
social
economic

TRAVEL:

Staff

Staff travel is budgeted at \$20,000 for FY 1989. Professional staff members are required to travel to meetings of the Council which are held outside of the District of Columbia. Two such meetings are projected for 1989. The Council also has assigned a high priority to holding Consumer forums in various cities nationwide to enable people with disabilities to express their views directly to Council members and staff. As in prior years, four such Consumer forums are planned for FY 1989. Staff members arrange and conduct these forums. Council staff members also participate in various professional meetings and conferences, and make site visits to facilities serving people with disabilities which are supported with Federal funds.

Council Members

The fifteen members of the Council receive, by law, reimbursement of travel expenses associated with the four meetings required annually and with such other meetings as the Council may schedule. Council members are also reimbursed for travel to meetings, forums, conferences, and other official functions where they represent the Council. Eighty-two thousand dollars is budgeted for travel by Council members in fiscal year 1989.

Advisors

The Council is committed to involving disabled leaders from across the nation as advisors to participate with the Council in many roles. The Council plans to involve a small number of advisors in all of its scheduled meetings and consumer forums during FY 1989. The Council will reimburse participants in these meetings for travel and per diem costs. No funds will be used to pay salaries for participants in these meetings. Twelve thousand dollars has been budgeted for travel related to this activity in FY 1989.

RENTAL PAYMENTS --GSA and Others:

The Council occupies 2,040 square feet of office space in the 800 Independence Avenue, S.W. Federal office building. The cost of this office space now averages \$31.00 per square foot. The Council has budgeted \$64,000 for occupancy costs in FY 1989.

The Council also budgets rental payments to the host agency, the U.S. Department of Transportation. Services received from DOT include: standard telephone services, building maintenance, building security, access to small conference and meeting rooms, access to high speed duplication equipment, mail room service, and certain audio visual services. Seventeen thousand dollars is budgeted for this item in FY 1989, \$6,000 of which is allotted for basic telephone services and equipment charges.

double entende

dupes > product of
rehab

dupes, & respect
for rehab prog.

Lay out issues
mainpoint based on eff

Ques & Ans. following

Yesterday we heard
outstanding ~~as~~ & challenging
press. about what could be
about how the most
surviving this people
can live successfully
& produce in the land.

We in Texas know it
can happen — some
of us have been involved
in model trans projects,
extended school, supported
work, low demands. etc.

But too often in Texas
well as elsewhere, we
are fixated in the 'Demor',
phase, dependent on grants
& year to year funding.

Roy Farley, Vernon Allen, Tom Thornton
Bobby Casper, Richard Petty

Thank ~~Jane Stark~~
But Simpson Mary Faithful
Big Girls Janet Marshall
Bob Mann
Paul Hearnshaw
Rick Plessen
Vince Bond
Gloria
H. H. Fleming
J. H. C. & other sons

Congrats

Shows opportunity
to share views
to be part of ~~outlet~~ ^{series} ~~outlet~~
excellent
Beyond what to deduce, ^{presenters}

Comm. Outing. There to stay

~~Long title & theme~~

Suggests permanent
~~standards~~ ~~suggests~~ ~~imp, need, commitment~~
~~Principles are~~
fundamental to
our interests & efforts

~~We should all subscribe~~
~~To & advocate for~~
~~them.~~

I doubt that we will
achieve what we know
we ~~to~~ should achieve
simply by trying to convince
ourselves & others that we
should achieve it,

Sound circular but the
point is:

We must act to
estab. principles in
law & to back up
principles w/ ~~merit~~ ~~and~~
program auth. & funding.

This has got a pol. security & ~~cost~~ ~~muscle~~
to this:

We must organize
& unite

org. across the lines

- Prog

- regional "

etc.

Choose leadership by consensus
leave behind leadership

ignore difs & commit to
common obj's, & interests
look @ ~~potential~~ already present
in the dif movement

~~Despite~~
despite the dif of our abilit
or those of our children
" of the people we serve
all of us have a ^{common} need for
or a desire to provide
habilitative services ←

home care
nursing care
educ.
couns.
adap. trans
" housing

AND

we are common victims
of

me of:

prejudice

Bigot

political
social
economic

} Disfranchisement

segregation

paternalism

dehumanization

Discrimination

Native ppl

~~We are all concerned
about services,
attitudes~~

We all want

opp. to set goals
& " to achieve "

Some of us want to work
~~others seek~~

" want to have fam.

Some of us want to
have better edu-
for ourselves & our children
+ ~~others~~ ^{some of us} have ^{other} equally ^{imp.}
goals of self fulfillment
& productivity

Together we are concerned
about - services
attitudes
rights &
opportunities

In recent yr - for the first
decade

we have been drawn away
from working together
to achieve collective goals
we've been encouraged
to & teased into

fighting among ourselves
competing or each other

were been sucked
or sucked into
turf battles between agencies,
orgs. bet. parents & cons.,
bet. cons & providers,
and so on

& by building upon
one another we've
succeeded in convincing
policy-makers, polit,
& com. leaders

that our needs are
not imp^a enough for
us to stop debating among
ourselves & develop ~~agreed~~ ^{agreed} ~~on~~ ^{on} ~~us~~ ^{us} ~~and~~ ^{and}
therefore not imp^a
enough to justify general
public concern or action

Instead of getting
generic
systems oriented
entitlement

— permanent solutions
to our concerns

We get common projects in
common funding
research projects
policy studies
~~expert consultants~~
consultant reports
+ planning grants

when we seek policy commitments
we get committees

when we seek program comm,
we get ~~for~~ model projects

& when we seek long term funding
we get empty promises
expenses

We talk empowerment
" revolution
" rights

But we still are tentatively ^{because of}
" powerless ^{frustrated}
" disorganized ^{we}

To achieve our common goal of
to implement our principles
of participation
inclusion
empowerment
+ rights

we have to:

promote ourselves @ leaders
build coal,

educ & do outreach

sense the power & the passion
feel the power
use the power

passion

@ Luke Skywalker might say:
"The Force is with us!"

Right now we have
perhaps the best
opp we've ever had
to create dramatic
change in the status quo
to influence ~~the changes~~

our whole soc,
to sys^{radically} improve
services & estab. a
basis in rights which will
permanently insure
those services.

ADA
TI history
ADA

S2345
HR 4498